Quality of life in families having children with disabilities: The parents' perspective.

Ilektra KOTZAMPOPOULOU

Master's Thesis
Master of Philosophy in Special Needs Education
Department of Special Needs Education
Faculty of Educational Sciences

UNIVERSITY OF OSLO

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Abstract

Background: Family quality of life is a recent concept in disability research. Living with a child with disabilities can affect everyday life in many ways. Researchers have mostly focused on the quality of life of the children with disabilities rather than the caregivers'. It is therefore interesting to explore the parents' opinions regarding their quality of life.

Objectives: The purpose of the study is to find out what parents of children with disabilities think about their quality of life in the family. Therefore, the objectives of the study are: To explore the parents' opinions regarding their quality of life in the family, to see how parents perceive that a child with disabilities affects their quality of life and to explore the parents' suggestions for improvement in their quality of life.

Design: A qualitative research design with semi-structured interviews and a hermeneutic analytical approach were used for this study. Five parents of children with disabilities were interviewed, in Chios Island, Greece.

Results: The data analysis revealed two meta-themes, seven themes and twenty one sub-themes. The two meta-themes represent the main findings and emanated from the interview analysis. Meta-theme 1, discusses the need for a disability oriented welfare system for all and meta-theme 2, argues the need for a relaxed everyday life with no stress. The main findings showed that the parents' quality of life depends on their children's disabilities. It also emerged that the parents feel disappointment and anger regarding the welfare support they receive from the state as well as fear for their children's future. Nonetheless, the parents reported somehow satisfied with their overall quality of life.

Conclusion: The study implies that there is a need for awareness-raising regarding the quality of life of families having children with disabilities. The state should provide laws and policies that are disability oriented as well as educate the community regarding the types of disabilities in order to support the most vulnerable families. These preliminary findings contribute to knowledge concerning the opinions of Greek families having children with disabilities regarding their quality of life. Moreover, they may prove especially helpful as a feedback to the Greek authorities regarding the families' needs.

Keywords: Quality of life, disability, family, parents' perceptions, subjective well-being.

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Ilektra Kotzampopoulou

http://www.duo.uio.no/

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“It's the action, not the fruit of the action, that's important.

You have to do the right thing.

It may not be in your power, may not be in your time, that there'll be any fruit. But that doesn't mean you stop doing the right thing.

You may never know what results come from your action.

But if you do nothing, there will be no result.”

Mahatma Gandhi

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Contents

Tables and Figures

1 Introduction

The Greek author Nikos Kazantzakis (1953, p. 86) has a memorable quote which describes the mentality of Greek people towards life:

"I felt once more how simple and frugal a thing is happiness: a glass of wine, a roast chestnut, a wretched little brazier, the sound of the sea. Nothing else."

Greece is a blessed country, with warm and long summers followed by mild winters. For years the citizens have been enjoying the profits of the Mediterranean climate and the benefits of a prosperous agricultural region. Simplicity, tasty food, wine and the sea was everything a person needed to be happy.

This quote links happiness to hedonic philosophy of Kazantzakis' ancestors, which will be discussed in the following chapters. The hedonic philosophy is focusing on the human senses and measures happiness with the amount of positive experiences one can achieve in life.

But what happens when a child with disabilities enters the family? Is it only the satisfaction of basic needs and avoidance of negative feelings that can bring happiness and a good quality of life in the family?

Unfortunately, families struggling with disabilities have not been given much attention in the Greek laws and legislations. It is therefore interesting to talk to families of children with disabilities and get them to share their experiences, fears and hopes as well as suggestions for improvement in the future.

With the present study I intend to explore the parents' views on their subjective well-being. I intend to see how they perceive that a child with disabilities affects their quality of life and to explore their suggestions for improvement in the family quality of life.

This chapter includes the outline and the background of the study. The notion of quality of life and family quality of life are going to be discussed. Moreover, it introduces to the reader the objectives and significance of the study. Lastly, the philosophical concepts of hedonic and eudaimonic views on happiness will be presented as well as historical information about Greece.

1.1 The outline of the study

The present thesis will be organized in six chapters.

Chapter 1 introduces to the reader the background as well as the objectives and the significance of the study. Some fundamental concepts such as hedonic and eudaimonic views of well-being are going to be discussed. Finally, there will be historical information about the Greek legislation and laws for people with disabilities.

Chapter 2 describes the theoretical framework and previous studies regarding quality of life in families having children with disabilities. It defines subjective well-being which is in the center of the focus of this study. The family systems theory is explained as well as the ecological systems theory by Urie Bronfenbrenner.

Chapter 3 outlines the design of this study. Information about the collection of the data, the description of the sampling process and data analysis are presented. Moreover, the notion of validity, reliability and ethics are presented in relation to this study.

Chapter 4 involves the presentation of the findings that emerged from the data analysis followed by a critical discussion of the results in Chapter 5.

Lastly, Chapter 6 argues the conclusion of this study as well as the implications for further research.

1.2 Background of the study

1.2.1 Living with a child with disabilities

It is no secret that raising a child with disabilities can affect family life in many ways both positively and negatively. Research has shown that levels of parenting stress might be increased compared to families having children with typical development (Dardas & Ahmad, 2014). Regarding the disability, there is always an impact in all life domains of the family.

Dardas (2014) discusses the challenges that parents of children with autistic syndrome face in their social life as well as their work place. The families with autistic children tend to withdraw from activities that include social contact. Moreover, some parents seem to choose

to quit their jobs in order to support their child together with the family members and professionals (Dardas & Ahmad, 2014).

In a study regarding the impact of having a sibling with an intellectual disability, the majority of parents also reported benefits to their other children such as: tolerance and acceptance of differences, caring and compassion, maturity, patience, assistance/support, appreciation of own life, health. The study proved that there are some factors that have impact on the family life such as: personality of the child, type of disability, family style, mental health, attitude and parental well-being (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008).

1.2.2 Disability perspective and human rights in Greece

The quality of life concept is very interesting from a disability perspective. Having a meaningful and happy life for every citizen of a country is crucial in order to have functional societies that create equal opportunities for all. Measuring life quality is a way to identify, evaluate and develop social services and policies for people with disabilities (Schalock, et al., 2002).

Greece has signed the European Convention on Human Rights, the Geneva Convention relating to the Status of Refugees and the United Nations Convention against Torture. In addition, the Greek constitution guarantees basic human rights to all Greek citizens. The Convention on the Rights of Persons with Disabilities intends to protect the rights of the disabled people.

Even though in Greece there are a lot of policies, laws and signed conventions about human rights and equal opportunities for all, people with disabilities are facing difficulties in everyday life. The family context may be the most important context for everyday life for most people, especially for children who are still dependent on their parents. Thus, the quality of life of the family is probably a prerequisite for quality of life of children with disabilities.

1.3 Quality of life

Felce and Perry (1995, p. 60) define quality of life, as:

"Quality of life is defined as an overall general wellbeing that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional wellbeing

together with the extent of personal development and purposeful activity, all weighted by a personal set of values."

Mark Rapley (2003) explains that the Felce and Perry model includes the following postulates. Firstly, quality of life is the same for all human beings with or without disabilities. Secondly, people understand the world differently and through their perceptions they define happiness in different ways.

Individuals' needs reform the meaning of quality of life. Quality of life is about enrichment of everyday life. Moreover, there is focus on the individuals' choices and needs but life quality is also influenced by environmental factors. Basically the framework has three fundamental features: the subjective and objective measurement, life domains, and the influence of personal values (Shearer, 2010, p. 207).

Cummins (1997, p. 6) argues that *"quality of life is both subjective and objective."* He proposes that both the objective and subjective axes should be explored. Those axes compound seven domains that cover the spectrum of the concept of quality of life: material well-being, health, productivity, intimacy, safety, community, and emotional well-being. The objective axis shows the people's real living conditions and the subjective the individual's personal evaluation of the domains of his life (Exenberger & Juen, 2014).

Eckermann (2012, as cited in Exenberger & Juen, 2014) states that there are two common areas in the definitions regarding quality of life. Firstly, it is to adapt a common understanding about the good life and secondly to integrate subjective and objective indicators in the concept of quality of life. Subjective indicators apply to personal feelings, opinions, beliefs and objective indicators are measurable things (Sirgy et al., 2006, as cited in Exenberger & Juen, 2014).

In the present thesis, I intend to explore the parents' perspectives regarding their quality of life through interviews. Therefore, I will measure the subjective areas of quality of life. The following definition from the World Health Organisation WHO Quality of Life Group's (WHOQOL) is used:

"An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations and standards and concerns. It is a broad-ranging concept affected in a complex way by the person's physical

health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment." (World Health Organization, 1997)

1.4 Family quality of life

In family quality of life studies, when the family includes a child with disability, intend to explore the parents' perspectives on how domains of their everyday life are influenced by the presence of a child with disabilities (Brown, Crisp, Wang, & Iarocci, 2006).

It is a fact that many children and people with disabilities spend most of their time at home. Sometimes their disability level is so major that their parents are responsible for the fulfillment of their basic needs (Sulch & Kalra, 2003). The literature related to quality of life is mostly focusing on the individuals with disability in order to create policies having those individuals in the center of attention. Nevertheless, the parents of the children with disability are also affected by their child's disability and their quality of life should be taken into consideration as well. Sulch and Kalra (2003) argue that there are partly different factors that affect the quality of life of the disabled child and the caregivers.

Brown emphasizes that the role of the family in society is very important, in order to keep it stable and functioning (2004, as cited in Werner et al., 2009). Therefore, having families that are satisfied with their life quality can improve the general quality of the societies. The quality of life of the caregivers is interrelated with the quality of life of the disabled child. It is therefore very important to be explored.

Research has shown that there are several factors that affect the quality of life of the caregivers: their feelings about their performance as a caregiver (Sulch & Kalra, 2003), possible physical health problems due to lifting (Carod - Artall et al., 1999, as cited in Sulch & Kalra, 2003), quitting their jobs and social activities (Jones et al., l992, as cited in Sulch & Kalra, 2003) and more.

1.5 The objectives of the study

The purpose of the study is to find out what do the parents of children with disabilities think about their quality of life, what challenges do they meet, and what should be done to improve

it. Therefore, I intend to explore how a child with disabilities affects positively and negatively the quality of life in the family.

This study aims at exploring the perspectives of the parents of children with disabilities regarding their quality of life. The objectives of the study are:

- To explore the parents' opinions regarding their quality of life in the family.
- To see how parents perceive that a child with disabilities affects their quality of life.
- To explore parents' suggestions about improvement of their quality of life.

1.6 Significance of the study

This study is significant because it is hoping to:

- Contribute to knowledge regarding quality of life in families having children with disabilities in Greece through the voices of the parents, which has not been given much attention in the scientific research.
- Raise awareness, regarding the challenges that the families face, to the public and the policy makers.
- Provide knowledge to the Greek authorities regarding the needs of the families.

1.7 Eudaimonic and hedonic views on happiness

The hedonic and eudaimonic views are philosophical concepts related to quality of life. Well-being, life-satisfaction, happiness, good life, enjoyment (…) are some of the terms that are often used interchangeably for quality of life (Rapley, 2003).

1.7.1 Eudaimonic view

The etymology of *"eudaimonia"* comes from the Greek word *"eu"* (good) and *"daimon"* (spirit). There have been a lot of discusses around the meaning of it, and a lot of difficulties in

the exact translation from Ancient Greek to English. Aristotle (Ryff & Singer, 1998, as cited in Exenberger & Juen 2014) describes eudaimonia as the:

"(..)Highest of all human goods as the realization of one's true potential."

Achieving eudaimonia is finding true happiness which for Aristotle is seen as the expression of virtue on doing what is worthwhile (Ryan & Deci, 2001).

Kenny (1992) argues that Aristotle understands happiness as the activity of the complete virtue in a complete life. Fromm (1981, as cited in Ryan & Deci, 2001) argues that Aristotle discriminates two needs in a person: The desires that lead to momentary pleasure, and the needs that differentiate people from animals that lead to eudaimonia.

Hughes (2001, pp. 22,23) proposes the use of *"fulfilled life"* or *"fulfillment"* in order to translate the meaning of eudaimonia and more specifically *"living a worthwhile life."* He explains that Aristotle claims that human fulfillment cannot be gained through money or pleasure. By pleasure, Aristotle means the physical pleasure. That is because fulfillment is something that differentiates human beings from animals. Moreover, the actions that the person should take aren't the ones that will bring him joy or pleasure but they are the ones worth taken. Therefore, it is not only the character of a person that leads to eudaimonia but the way he acts and the decisions he makes in life. A fulfilled life will bring joy but also a life that is worthwhile. Hughes (2001) explains the two characteristics of eudaimonia as the fulfilled life is sufficient of itself, and that it is the perfect end.

1.7.2 Hedonic view

In the 4th century BC, a Greek philosopher Aristippus argued that every person must aim at experiencing the biggest amount of pleasure in his life. Therefore, happiness is the sum up of a person's hedonic moments (Ryan & Deci, 2001).

Epicurus (342-270 B.C) adopted Aristippu's hedonic theory about life, that hedonic pleasure is the highest experience that a person can achieve. The epicurean hedonic view is based on the human senses.

The book Ancient Greek Philosophy (Niarchos, 2005)gives us an overview of the ethics of this philosophy. The beginning and ending of a good life is hedonic pleasure. A person's duty is to learn how to enjoy its benefits. Epicurus' philosophy has been misconstrued through the

years. The *"good hedonist"* for Epicurus is someone who follows his senses but never overdoes it (Niarchos, 2005, p. 150). Doing immoral things is not what he meant. That is because Epicurus argued that bad attitudes can lead to bad feelings. Bad feelings are not indicators of happiness so they are not preferred. A person's basic needs should always be fulfilled but an excess life should be avoided.

Happiness for Epicurus isn't money, or holding a high position is society, but avoiding pain. Therefore, the quality of the hedonist's experiences is responsible for their well-being (Exenberger & Juen, 2014).

Hedonic psychologists measure the pleasant or painful experiences of a person with the assessment of subjective well-being (Dieber & Lucas 1999, as cited in Ryan & Deci, 2001). The subjective well-being is therefore happiness.

For the hedonic psychologists subjective well-being involves life satisfaction, the presence of positive mood, and the absence of negative mood (Ryan & Deci, 2001, p. 144). Subjective well-being is a term which is going to be presented on the next chapter. People such as Hobbes, Desade and Bentham followed the philosophical hedonism (Ryan & Deci, 2001). Well-being is a subjective matter of happiness (Haybron 2008, as cited in Exenberger & Juen, 2014).

To conclude, Aristotle is focusing on living a good meaningful life when the hedonic perspective is focusing on getting the bigger amount of pleasure and avoiding negative feelings.

Graham (2011) suggests that there can be a distinction between people who have the capacity to change their life conditions and those who cannot. He (Graham, 2011) argues that the Aristotelian perspective on happiness can be applied in the process of policy making. To enrich people's quality of life, the state can provide policies who aim at creating meaningful experiences for people who have the possibility to change their lives. That is to enable them to reach their optimal level of potential. Those policies are focusing on the long-term happiness. Examples can be the improvement of laws in education and reforming the welfare system etc. On the other hand the hedonistic philosophy can be applied in policies regarding short-term experiences for people who do not have the ability to change their life conditions such as leisure opportunities or policies for the disabled people regarding their late life stage.

1.8 Historical information about Greece

1.8.1 Modern Greek history: A short description of economic - political disruptions

Modern Greek history has a beginning point on the Greek war of independence against the Ottoman Empire (that lasted from 1453- 1821) until today. In my opinion getting a short description of the modern Greek history will give a better understanding of the context on which laws and legislation occurred for families having children with special needs. The dates and events introduced are based on Clogg (1997).

Dates	**Events**
1821-1822	1821: Greek Revolution against the Ottoman empire. 1822: Declaration of the first constitution of independent Greece.
1827-1831	1827: I. Kapodistrias, the first governor of Greece, makes an effort to improve the economy and education. Greece gets recognized as a state named "Greek State." 1831: I. Kapodistrias gets murdered.
1832-1862	1832: *"Monarchical and independent"* state of Greece assured by the Great Powers (England, France, Russia) with the reign of the 17 years old Bavarian king Otto. 1862: Army rebellion, King Otto forced from throne.
1893	Greece defaults on external loans.
1909	Military coup leads to downfall of government.

1912-1913	1912: First Balkan war (Greece, Serbia, Bulgaria, Montenegro against the Ottoman Empire). 1913: Second Balkan war (Bulgaria against Greece and Serbia).
1915-1918	First world war.
1919-1922	Greco-Turkish War.
1925-1926	Establishment of dictatorship by Pagkalos.
1933	Unsuccessful coup by Colonel Plastiras.
1936	Establishment of dictatorship by Metaxas.
1940-1944	Second World War – German occupation.
1946-1949	Civil War.
1967-1974	Military coup by Colonel Papadopoulos.

Table 1. Major economic and political disruptions in Greek modern history, own-created based on Clogg, 1997

1.8.2 Greek legislation for children with disabilities and their families

As we can see from Table 1, after the Greek liberation in 1822, the country continued to be unstable with external loans, wars, dictatorships. Therefore, no legislation regarding people with disabilities and their families occur until 1975.

Before 1950s, people with special needs in Greece were considered *"a threat to societal security"* (Syriopoulou-Delli, 2010, p. 2). People with developmental or behavioral disabilities were protected by their families and did not have any civil rights at all. Those children did not get any education or proper treatment from the state. Second World War had a negative impact on the country's political and economic stability as well as to the people's attitudes. There were no infrastructures, nor working force to organize the country's issues and therefore the educational system (Syriopoulou-Delli, 2010).

Scientists and educators were focusing on research regarding children who have been traumatized after the civil war and from the late 50s medical centers were established (Syriopoulou-Delli, 2010).

Around 1960s, children of school age who were *"mentally retarded"* were getting education and psychotherapy inside clinics and hospitals (Syriopoulou-Delli, 2010, p. 3). The attitudes regarding children with disabilities and their families started to change gradually. But only the attitudes and the private sector was showing interest in explicit change. The government did not take any consideration of the treatment of those children and their development and their families.

The laws related to special education have a starting point in 1975, when for the first time the rights of children with disabilities are guaranteed through the constitution. The first complete law in the history of Greek education for children with special needs was in 1981 (Greek Official Governmental Gazette, 1981).

After a few years, in 1985 (Greek Official Governmental Gazette, 1985), special education becomes an integral part of the educational system and integration is promoted through the creation of special classes within the mainstream school. The first time that the families of children with disabilities are mentioned occurs with the Law 2716/99 (Greek Official Governmental Gazette, 1999). The article 9 of this Law provides psychosocial rehabilitation for children whose parents are not able to take care of them with units such as: boarding houses and schools and host families.

For the diagnosis of the children, the Law 2817/00 (Greek Official Governmental Gazette, 2000) establishes centers of Diagnostic evaluation and support. Children with disabilities have the right for free evaluation from these services. Therefore this is the first law that indirectly focuses on the families and provides free diagnosis and support. Nevertheless those centers are a very few and they do not actually support all the families.

Finally, the Law 3699/08 (Greek Official Governmental Gazette, 2008) *"Special education for people with disabilities or special educational needs"* combines all previous laws and leads to a form of legal unity with overall national policy on education. The Law 3699/08 (Greek Official Governmental Gazette, 2008) is based on the internationally recognized attributes of one school for all and the principles of the European Union for the integration

and equality of opportunities. The term of *"early intervention"* for preschool students is introduced to the Greek educational system. Differential diagnosis is institutionalized with centers of differential diagnosis and support (KEDDY). In practice those centers aren't able to support all families due to lack of organization and educated staff.

With FEK 134 (Greek Official Governmental Gazette, 2004), an overview of the disability categories that are entitled state welfare support is introduced. The prerequisite for the support is that the person isn't working with the exception of blind and paraplegic, quadriplegic. The amount of money that the families of disabled children are qualified for isn't stable. Moreover the benefits are deposited every two months. In summary the welfare support is for children with:

- Severe mental retardation
- Mild mental retardation
- Autism
- Cerebral palsy
- Paraplegic- quadriplegic
- Severe disability
- Deaf mute
- Thalassemia- hemolytic anemia- hemophilia-aids

Those benefits are very important for the families with a disabled child in the Greek society. We will see later on the interview analysis that the benefits since 2009 have been dramatically decreased and families with poor income are struggling in everyday life.

2 Literature review

2.1 Introduction

In this chapter, theories about well-being and the meaning of subjective well-being will be introduced. Attention is also given to the definition of family and developmental theories about the family as a social system (Hill, 1971), the way it functions and how the family's well-being is influenced by the society.

Urie Bronfenbrenner's ecological systems theory (1979) is seen as a relevant frame for the discussion. The specific processes that take place between the systems that affect the quality of life of the family, can be seen from the sociocultural developmental framework.

Lastly, previous research findings on the quality of life of families having children with disabilities will be presented.

2.2 Defining well-being

There are a lot of definitions that can be found in the literature regarding well-being. As explained in the background, the meaning of well-being has its roots in Ancient Greece with the hedonic and eudaimonic philosophies.

In the present thesis, I will refer to definitions taken from the sociological and family literature. Zimmerman (2013) cites some of the definitions which include people's satisfaction in certain life domains such as jobs, families, marriage, leisure and housing (Andrews & Withey 1976; Retting 1983 et al., as cited in Zimmerman, 2013) and their attitudes towards their lives , positive or negative (Inglehart 1990, as cited in Zimmerman, 2013).

Griffin (1986) argues that another way of defining well-being is regarding the fulfillment of basic needs of a person in everyday life in order to survive and avoid pain (as cited in Zimmerman, 2013) which is related to the hedonic view. Some others add the importance of socialization in the developmental processes of a person in a specific environment which affects their well-being (Herzog et al., 1982, as cited in Zimmerman, 2013).

The two philosophical perspectives of well-being are discussed by David Phillips (2006, as cited in Sirgy, 2012) who is a philosopher of happiness. The hedonic approach focuses on the individual's perspective regarding his own opinions about what brings happiness to his life. On the other hand the Aristotelian eudaimonic perspective comprises the continuous attempt to achieve a person's full potential, to be a sensitized citizen and to reach the optimal levels of decency.

In the present thesis, I will explore the parents' opinions regarding their quality of life. Therefore, I will focus on their subjective well-being and how the support provided by the state affects their short and long-term happiness as discussed by Graham (2011).

2.3 Subjective well-being

The meaning of subjective well-being implicates the individual's perspective about his/her life as a whole. It can be found in the literature as happiness, life satisfaction, enjoyment etc. In the present thesis the parents are going to be asked about their opinions regarding their quality of life, therefore the focus will be on the individuals' perceptions about their lives. This is the so called subjective well-being.

Bowling (2005) argues that a well-being of a person can only be understood by asking their opinions about their life. This can be measured through the subjective indicators. The subjective indicators may *be "feelings, attitudes, preferences, opinions, judgements, or beliefs"* (Sirgy et al., 2006, as cited in Exenberger &Juen, 2014, p.5).

Diener & Suh (1997) perceive those social indicators as a natural evolution of the idea of subjective well-being as a person's *"hedonic feelings or cognitive satisfactions"* (as cited in Bowling 2005, p.6).

Moreover, Diener (1998, as cited in Exenberger & Juen) explains that asking people about their subjective well-being gives the researcher a better overview of their life quality. He also describes well-being as a *"democratic"* (2002, p. 64) concept because it respects people's opinions on how they evaluate their life instead of using professionals to do it for them.

There are three types of theories regarding subjective well-being that are going to be discussed briefly based on Diener et al. (2002):

- The need and goal satisfaction theories: These theorists argue that happiness can be achieved by avoiding negative feelings such as pain and through the fulfillment of the basic biological needs. Moreover, the importance of having goals in life and moving closer to them is very significant for their happiness.

- Process or activity theories: They agree with the above theorists and add "*active participation in life tasks"* (Diener, Lucas, & Oishi, 2002, p. 66). Therefore, the subjective well-being depends on the changes that occur on people's lives when they are involved in activities or achieve their goals (Diener, Lucas, & Oishi, 2002).

- The genetic and personality predisposition: These theorists add the genetic component in the evaluation of subjective well-being. They believe that there are some personality dispositions that are stable and do not depend on the changes that occur on a person's life (Diener, Lucas, & Oishi, 2002). Those dispositions have influence on the way people react to changes in their surroundings.

Diener et al. (2002, p. 63) argue that the concept of subjective well-being includes the experience of more positive than negative emotions and high life satisfaction. It is discussed (2002) that there are two types of life satisfaction that can be measured: The evaluation of momentary experiences and a global assessment of one's subjective well-being. Therefore, their momentary feelings might be pain or joy, fulfillment etc. regarding a specific experience. A more broad measurement of well-being is through people's general idea about their life as a whole. He summarizes that a person's evaluation of each domain of his life is dependent on people's beliefs and is influenced by society.

Diener et al. conclude that *"the way people perceive the world is much more important to happiness than objective circumstances"* (2002, p. 68).

2.4 The definition of family

"Families are two or more people who share the same goals and values, are committed to one another over the long-term, and usually live in the same household" (Zimmerman, 2013, p. 10).

Based on Zimmerman (2013) family can occur in many ways: married couples, single parents, step-parents, blended, adopted parents/children, heterosexual or homosexual families

etc. Nevertheless, the difficulty of making a concrete definition comes from the fact that the concept of family changes over time. Depending on the time and culture, the family has had different structures. From a developmental perspective, the family is seen a system which is characterized by its unique patterns of interaction between its members (Anderson & Sabateli, 2007).

Therefore, the families are identified by their own unique ways of executing specific tasks over time. These tasks establish specific patterns that are unique, create bounds between the family members and society, regulate the household management and promote the quality of family's emotional well-being (Anderson & Sabateli, 2007).

2.5 Family systems theory

The family systems theory is a developmental approach that conceptualizes the family as a social system. It explains the family unit as a social system which is organized to meet the needs of its members and society's. It will help through understanding how is the family organized, what happens between the members and how it affects their well-being. Hill (1971) discusses that family is a social concept with the following properties:

- The family members have different roles and they are characterized by interdependence. Each member of the family has a different role and position that is basic for the family system to function. These are: husband, wife, brother, sister, mother, father, daughter, son etc. These roles are reciprocal and interrelated, which means that a change in one member's role brings change to the others (Hill, 1971). The members having each role are interacting with each other and based on the unique characteristics of each family, they manage to satisfy their needs and make them functional for society (Zimmerman, 2013). The families may differ from the culture and social class they come from (Zimmerman, 2013). Litwak (1985, as cited in Zimmerman, 2013) adds that the family network does not cease to exist even when the members of the family are separated from each other. This happens through technological achievements that support e.g. the parental role when a child studies abroad etc.

- The family is a closed unit, with boundaries to differentiate from the others. Hill (1971, p. 14) views the family as a *"semi-closed system."* The family members are

united by same values and expectations and they make boundaries between them and the outside world. Aside from the family roles, the members of the family create liaison roles to link them with society. E.g. the role the mother creates with the child's school.

- The family seeks equilibrium and is adaptive to changes. The family system as mentioned above create a *"network of interaction patterns"* (Hill, 1971, p. 15) that help them communicate with each other and with society and are unique and based on shared values and goals. The equilibrium seeking means that the family needs to create new roles based on the demands of the outside world. This means changes in behaviors that affect the whole family and does not satisfy all members. In that case the family has to create its own techniques to handle the conflict that occur in the family. Hill (1971) argues that the repetition of the new behaviors produces equilibrium in the family. Therefore, the family system is adaptive to change in order to find the balance between its members and society.

- The family performs tasks which serve the needs of its members as well as society's. These tasks are fulfilled in different ways and depending on the phase the family is, importance is given to different tasks. Hill (1971) discussed that the basic tasks that the members of the family perform are the following:

    - The physical maintenance of the family members
    - Adding new members in the family through giving birth or adopting and releasing them when they reach the level of maturity.
    - Socialization of children for adult roles
    - Be sure that the order is kept inside the family and with the outside world
    - Keeping the motivation and confidence of family members high in order to perform the tasks in the family and with the outside world
    - Production of the necessary goods and service to keep the family members united

To sum up, the family members are interdependent. They share the same values and expectations and based on these, they build up a network of interactions and roles in the family. They make boundaries from the outside world and also create mechanisms for surviving in it, through adapting new behaviors.

They also perform tasks to keep the family united and with a good quality of life. These tasks are performed in different ways over time, by given importance regarding the phase that the family is in. Zimmerman (2013) adds that it isn't only the characteristics of the family members that define it but also the culture and the socioeconomic background of the family.

From this developmental systems theory the family well-being can be measured through the effectiveness of the family in the following: performing tasks, socializing, social control, physical conservation, economy, self-esteem, the membership functions and all this through time (Zimmerman, 2013).

The family exists in a nested set of ecological systems. Therefore the family quality of life is affected by the performance of the family as a system as well as by the interaction with other systems and society. There are tasks that the family members might have to do in order to keep the family functioning and stable.

It isn't only the relationship between the family members that affects their quality of life. The society on the other hand, with the provided support may affect the quality of life of the family due to the interdependence of the family members. As a result if the state does not provide support for those families, their quality of life will be affected.

2.6 The ecological systems theory

Urie Bronfenbrenner considers the world as an ecological system in which human development occurs (1979). For Bronfenbrenner, every individual is seen as an active human being who interacts with its surrounding and, not only gets affected by it, but reforms it. Therefore, the relationship between the individual and the environment is characterized by "*reciprocity"* (Bronfenbrenner, 1979, p. 22). The ecological environment consists of five subsystems that the one is contained within the next. Interaction between them occurs as well as from outside influences.

In the present thesis, I intend to explore the parents' opinions about their life quality in the family. Bronfenbrenner's theory (1979) is relevant because the family system is interacting with other systems such as school, work, friends, laws etc. and all these affect the quality of life of the family. Therefore, it is interesting to see how these systems are interrelated and they affect one another.

First of all, Bronfenbrenner (1994, p. 38) argues that human development is an outcome of *"complex reciprocal interactions"* between the individual, other people and objects of the environment. These interactions which are formed on regular basis are called "*proximal processes"* (Bronfenbrenner, 1994, p. 38). Secondly, he claims that the significance of these proximal processes is based on the individuals' characteristics, on the environmental context and on the nature of the developmental products (Bronfenbrenner, 1994).

Research on the *"process-person-context"* model has for example shown that the quality of mother to child care across time is very significant for the child's development (Drillien 1963, as cited in Bronfenbrenner 1994, p.38). It is mentioned that the strength of the processes vary in accordance with several factors like social class and the characteristics of the individual.

Moreover, the results of the proximal processes are more important for the individual than for the environment in which they take place. The development of an individual occurs in the ecological system which contains subsystems. These are the microsystem, the mesosystem, the exosystem and the macrosystem which are illustrated below:

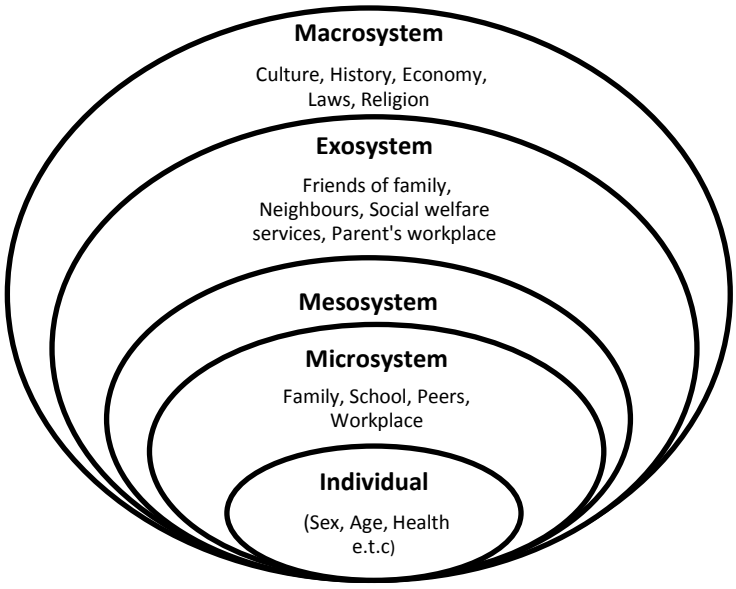

Figure 1. The ecological systems theory, own-created based on Bronfenbrenner, 1979

As Figure 1 shows, the individual is on the center of the ecological systems. The *m*icrosystem is the place where face to face interaction occurs. It comprises of: *"the activities, roles and interpersonal relations experienced by the developing person"* (1994, p. 15).

An example is the relationship within the family members, such as between the parents and the child. Examples of microsystems are the family, school, work place, peer group. The family which is the focus of this study is a system in which the members interact with each other and their interactions are significant for their quality of life. All members of the family are interdependent and have different roles.

The mesosytem includes the relationships that for example one parent creates with the child's school. Therefore, this relationship will affect the child's interaction with the teachers and his everyday life in general.

The relations between the members as well as the interaction with the other systems influence the family's quality of life. A child with disabilities for example, can influence the parents' social interactions with friends or at their workplace which is placed in the exosystem.

The macrosystem includes the culture in which an individual lives: The socioeconomic status, laws and regulations, the ethnicity, religion, political decisions etc. It affects their quality of life and is more complex for them to change. Laws, or religion and in general the political background of a country cannot change easily but it affects the families' quality of life.

2.7 Previous research

Family quality of life is a relatively recent concept in disability research. In Australia (Rillotta, Kirby, Shearer, & Nettelbeck, 2012), the results of a study showed that families were generally satisfied with all domains of their lives giving importance to the family relationships, while they were shown to be neither satisfied nor dissatisfied with their financial well-being.

In Belgium the results shown that parents were satisfied with the professional support they received from services but were skeptical on the support they received from other people (Steel, Poppe, Vandevelde, Hove, & Claes, 2011).

The results of a study in Nigeria shown family relationships, health and influence of values were a source of family quality while the following areas were problematic: support from services, support from others and leisure (Ajuwon & Brown, 2012).

A study of assessment of family life quality in families with intellectual and developmental disabilities in Slovenia showed that the family members find importance in all domains of life regarding their life satisfaction and they rated as the most important domain of life the family relationships. It is showed that they lack opportunities though in getting a better life quality (Cagran, Schmidt, & Brown, 2011).

Moreover, another study by the ministry of the Flemish community in Netherlands showed that both parents and adolescents rated high on their satisfaction with their subjective quality of life but low on the objective standards (Migerode, Maes, Buysse, & Brondeel, 2012).

All studies showed the importance of family relationships in relation to the family's quality of life. In countries such as Australia and Belgium where the socioeconomic status is higher, families seem to be satisfied in most of the domains of their lives as well as by the support they get from the disability services. Nigeria families on the other hand emphasize the importance of values in their lives while they lack support from disability services. Slovenia families also mention their uncertainty about their children's future due to lack of opportunities for a better economic status.

A similar study in Rhodes, Greece (Tsibidaki & Tsamparli, 2007) has shown that the families of disabled children do not feel supported by the social structures and they have a feeling of insecurity and anger regarding the general support from the state. On the other hand, they feel very satisfied with the support they get from their existing support networks, meaning their extended families. They also feel satisfied with the support they get from the faith in god, their relationship with the priest and other families of disabled children.

Interviewed mothers of a study regarding the adaptability and cohesion of families with children with disabilities, reported that their husbands become the real helpers when a new problem arises in the family. It was shown that the families due to lack of support from the state, they turn into their extended families to get the support they need (Tsibidaki & Tsamparli, 2009).

Another study regarding parental satisfaction with early intervention services for children with visual impairments and multiple disabilities in Thessaloniki, Greece resulted in high levels of parent satisfaction regarding specific early intervention services (Neofotistou, et al., 2014).

Another study, from Ioannina Greece, showed that parents of children with chronic neurological diseases do not speak out for their problems very easily while religion and values are very important to them. Those families have financial problems that they see it as a burden and are less satisfied from the support services than the families of children with epilepsy (Tzoufi, 2005).

From these studies we can conclude that in Greece the levels of support from the services aren't sufficient. Families with visual impairments get supported by intervention services when parents of severe disabilities aren't satisfied from the support they get. Moreover the financial well-being of the family is very important on the members' life as well as the impact of religion and values.

Those families in order to get the support they need they turn to their extended families. This is an example of *"family-centered help giving practices"* argued by Dunst (2000, p. 100). The family intervention system aims at supporting the family members by using each member's capacities towards the achievement of specific goals.

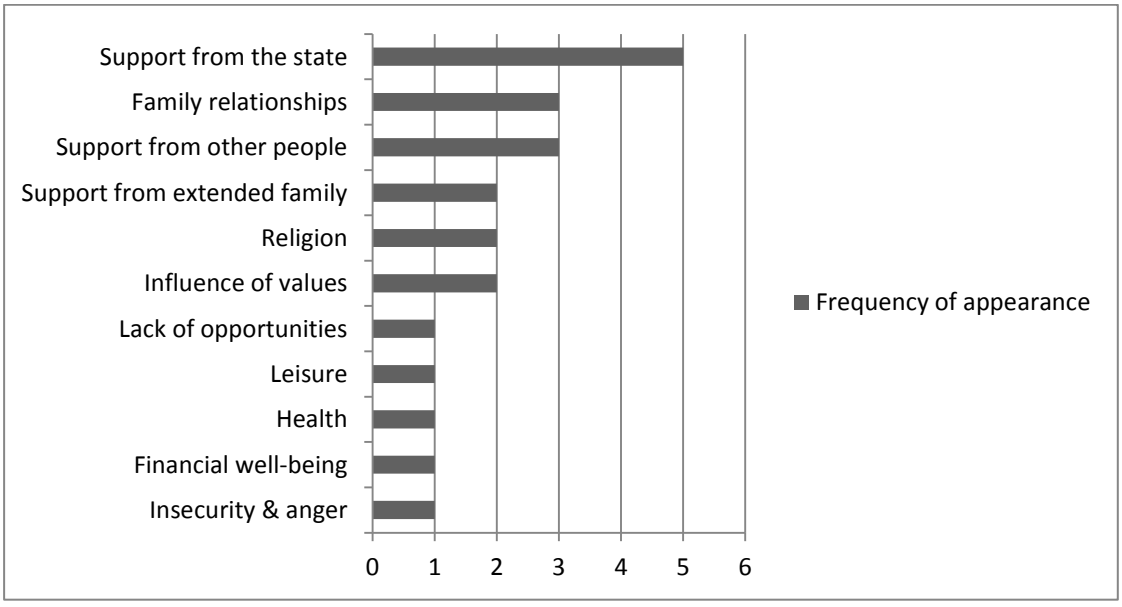

Figure 2. Themes discussed in previous research regarding family quality of life, own-created

In Figure 2, there is an overview of the frequency of appearance of specific themes in previous research. It is clear that the support from the state and the relationships with family members, extended family members and friends are the most frequent themes, on studies regarding quality of life.

Religion and influence of values follows as an important aspect in people's lives. More specifically in Greek families, people who struggle with problems tend to go to church and have good connection with a priest. In this way they feel that they get support from having faith in God.

Moreover, people seem to report lack of opportunities in everyday life in order to get a job as well as socialize and take part in recreational activities. Health, financial well-being and feelings of insecurity and anger are themes mentioned not as frequent as seen from the figure.

3 Methodology

3.1 Research method

"Words can be complicated symbols loaded with cultural meanings" (Rubin & Rubin, 1995, p. 21).

A qualitative research design with semi-structured interviews and a hermeneutic analytical approach will be used for this project.

The reason for choosing a qualitative research design is the nature of the research questions. To investigate the parents' opinions about their family quality of life is to listen to their stories. In qualitative approaches the researcher is interested in understanding the context in which the participants are and how it influences their lives (Maxwell, 2005). Therefore, a qualitative approach will give a more in depth understanding of people's experiences and opinions regarding family quality of life.

The hermeneutic approach is focusing on the meaning of the individual's experiences in an interpretive way (Patterson & Williams, 2002). Gadamer (1984, as cited in Patterson & Williams, 2002, p.22) argues that the interpretive activity between the experience and the meaning of it consists of two *"horizons"*: The actor's horizon which is the text and the reader's horizon which includes the researcher. In this approach the researcher has in mind the importance of the context in which the actors had their experiences. Having as a starting point their stories the researcher can go back and look at the context and get a better understanding of the meanings of the actors' experiences.

3.2 Data collection

The hermeneutic approach focuses on the meaning of the qualitative data and aims at understanding. Face to face interviews are the main method of collecting data. The interviewer pursues knowledge by carefully conducting questions and listening to peoples' answers (Kvale, 2007).

Vygotsky (1987, as cited in Seindman, 2006, p.7) argues that "*every word that people use in telling their stories is a microcosm of their consciousness.*" I believe that by listening to

people's stories I will get a deeper understanding of the situation for the families. The stories will reflect the culture that these people are living in and through my personal experience in Greece, I will be able to understand them and get the information I need from the interviews.

In a hermeneutic approach the researcher seeks to gather systematic data from the interviewees in a constructivist way. It is a process in which both interviewer and interviewee play significant roles.

A semi-structured interview guide enables the researcher to cover certain themes without forcing specific answers or meanings on the respondent. The guide is only used for what Charmaz (1981) argues to be a *"directed conversation"* (as cited in Patterson & Williams, 2002, p. 43). In semi-structured interviews the researcher follows a basic line of questions but also has the freedom on the questions that will follow (Freebody, 2003, p. 133). Furthermore, the order of the questions is not strict and the questions are open-ended giving the interviewee some space to develop his/her ideas (Denscombe, 2007). Open-ended, semi-structured interviews are a way to collect data in a "*raw*" state (Denscombe, 2007, p. 93).

Interviews took place in quiet, private places depending on agreement with the interviewees. All interviews were digitally recorded.

3.2.1 Sample - participants

In hermeneutic approach there is not any specific sampling principle but there is emphasis on the *"representativeness"* of the sample (Patterson & Williams, 2002, p. 41). Hermeneutic studies are more focused on the range of experiences rather than on the statistically generalization. Therefore the sampling for this research is made by purposeful sampling.

To achieve representativeness in my sample I set the following criteria:

- The families are residents of Chios Island in which the study is conducted
- The families have a child with disabilities
- Variation on the age of the children whose families are going to be interviewed (4-20 yr.) to get a wide range of experiences.

3.2.2 Researcher's bias and preconceptions

The hermeneutic analysis involves reflection on the researcher's preconceptions and experiences. Therefore, I believe that it is interesting to describe some information regarding my personal background.

I have been born and raised in Greece. In primary school I had a good friend with autism who was considered as a *"very difficult child."* I remember my parents discussing the problems that this child's family was struggling with. The state could not decide if the child should get education in a mainstream school or a special school. He was finally placed in a special school after finishing the 2nd grade of high school. I never heard about him ever since.

I remember that families with disabilities were never too open to discuss their problems while at school, the attitudes weren't always positive regarding children who were different in the classroom and they needed support.

Moreover, as a citizen of Chios Island, where this study was conducted, I have seen and experienced the disappointment and difficulties that families of children with disabilities face in everyday life.

The whole island seems to have been built without considering people with disabilities. For example, not all pavements are accessible by people on wheelchairs, there aren't enough parking lots for disabled people and aren't always respected by those with no disabilities. Many schools are built on 1st and 2nd floors and are not reachable for people on wheelchairs due no elevators. Moreover, there is no infrastructure for the blind people on the streets.

To sum up, I believe that my personal experiences can be very helpful through the interpretation of the results by reflecting on them through the whole process.

3.3 Preparing the interview

3.3.1 Preparing the parents

Before doing the interviews I had an informal conversation with two participants of the sample. First of all, I specified the topic and the purpose of the study. I also informed them about the nature of the interview questions and that the interview is going to be recorded.

Moreover, an overview of their rights was given, through a letter of consent (see Appendix A), and that they are participating voluntarily and that they can stop the interview whenever they want.

Informing the parents beforehand created a positive atmosphere between the interviewer and the interviewees which is essential. Indeed, those two parents introduced me to the other three families through their network.

3.3.2 Pilot interview

Before having the interview I conducted a pilot interview. Piloting an interview is like having a "*dress rehearsal*" (Gillham, 2000, p. 55). The rehearsal showed the productivity of the interview and its proximal length. The participant wasn't chosen from the sample. The pilot interview was a very helpful tool for practice of my interview skills, to see the proximal length of the interview and change any not well formulated questions.

After conducting the pilot interview I had to rewrite some of the questions because they were not completely understandable from the interviewee. Therefore the interview guide was revised. For example one of my questions was: *"What is quality of life?"* The interviewee did not understand exactly what he was expected to answer. Therefore I reformed the question on *"How do you define quality of life?"*

3.4 Data analysis

After each interview the recording was immediately transcribed. The transcribed data of all 5 interviews was a total of 46 pages. The data analysis was initiated after all 5 interviews were done. The interpretation of the meaning of the text is based on Tesch's *"organizing system"* (Patterson & Williams, 2002) and Geanellos's hermeneutic model of analysis (2005). To analyze the text, I used MAXQDA, which is a software program for organizing and analyzing qualitative data.

The steps I followed in the analyses are the following:

- Complete exact transcription of recorded data in order to create a "dialog" with the text. Paying attention to the tone of the voice and reading the text as a whole (all

interviews) over and over again. All word documents were inserted in MAXQDA which is a qualitative software program for data analysis.

- I start the analysis by looking at the text as a whole (all interviews). The first step I engaged in is called "*reduction."* Phrases and words of the interviewees were conceptualized into specific meanings, called fragments.

- The second step is called "*integration."* Fragments with the same meanings were grouped under sub-themes. I ended up with 80 sub-themes. Words of participants were used in naming sub-themes. Finally, the sub-themes were clustered into themes.

- In the third step I applied *"aggregation."* I looked at the fragments, subthemes and themes in relation to the whole text and created the meta-themes. On the present study 2 meta-themes, 7 themes and 21 sub-themes emerged.

- The fourth step involves the illustration of an organizing system (see Table 2) which is the product of the analysis. The organizing system is the presentation of the themes and sub-themes that emerged from the data analysis.

- Lastly, the discussion of the findings concludes the process of the data analysis

In this process the pre-conceptions of the researcher were treated as significant influences and were used while interpreting the data (Johansson, Hanson, Runeson, & Wåhlin, 2015)

3.5 Validity and reliability

3.5.1 Validity

In the present study I followed the research example of rich data which according to Maxwell (2005) is when the data is detailed and complete enough to provide a full and revealing picture of what is going on. After recording the audio, I transcribed the audio recording and then listened to the recording over and over again while reading the transcription to ensure descriptive validity.

Before taking the interviews, I ensured that my interview guide was formulated in a manner that led to my research questions. Thus, a pilot study secured the descriptive validity of the data gathered.

The second type of validity is the interpretive validity which focuses on the participants' perspectives. The method I used to secure interpretive validity was member checking by sending the transcribed text to the interviewees to confirm the accuracy of the text.

3.5.2 Reliability

In general reliability is related to quantitative research where it is more possible to check the research findings than in the qualitative. However, there are two types of reliability that I will discuss about the present study.

Firstly, the internal reliability *"refers to the degree to which other researchers, given a set of previously generated constructs would match them with data in the same way as did the original researcher"* (LeCompte & Goetz , 1982, p. 32) . To secure internal reliability I used tape recorders.

Secondly, to secure internal reliability, peer review was conducted. During this process I discussed with another colleague of mine the research process and my findings. This process helps the researcher get a deeper look in the data analysis and also aims at recognizing if the themes created are answering the research questions.

Lastly, external reliability refers to the replication of studies. To secure it I clarified the researcher's bias and preconceptions, the sampling process and the methods of data collection and data analysis step by step.

3.5.3 Ethical considerations

To conduct an interview study in Norway it is required that a research proposal is sent to the Norwegian Ethical Review Board (NSD). By the end of August 2014, I received the notification of approval of the study (see Appendix 3).

Kvale (2007) discusses the ethical considerations that should be taken into account in social research. Informed consent, confidentiality of the interviewees, consequences of participation in the project and the researcher's role in the study were included.

A letter of consent (see Appendix A) was given to the participants before the interviews. The letter included the purpose of the study and the interview procedure. A letter of consent should include possible risks and benefits of the participation on the study. Therefore, the participants were informed how I intend to secure confidentiality of their personal data as well as about my intentions of sending them a copy of the study when it is completed. They were also informed that they can withdraw from the interview any time they felt to do so.

Regarding the notion of confidentiality, I ensured the parents anonymity. This study does not publish any private information that can be recognizable by others. It did not use or publish any sensitive information and therefore there isn't a matter of possible negative consequences on the participants. The principle of beneficence (Kvale, 2007) is secured and the risk of harm to the participants reduced.

Lastly, the integrity of the researcher affects the quality of the research study. I believe that my previous experiences in Greece as well as my morality as a person, with respect to the interviewees, resulted ethical decisions while gathering and interpreting the data.

4 Presentation of the findings

4.1 Organizing system of analysis

Meta-theme I: The need for a disability oriented welfare system for all	
Themes	**Sub-themes**
1. Support from the state: The challenges the parents meet in their everyday life and their suggestions for improvement of policies regarding the families with children with disabilities.	• Lack of organization and infrastructure: *"My daughter, at the moment, apart from going to school does not have anywhere else to go, there are no swimming courses nor other sports that she can participate."* • No easy access on health services: *"You know how difficult it is to say to the child that we have to go for a trip to Athens to see a doctor? It's not only the financial cost but also the psychological difficulties for us and for the child."* • Disappointment and anger: *"they provided us a bus (for the children) which was a wreck. This was a crime."* • No easy access on getting financial support: *"There is a welfare support system but the process of applying and getting the percentage of the child's disability*

	is exhausting." • The need for laws regarding families with children with disabilities: *"Quality of life is a well-governed state with laws where both citizens and governors live their lives by obeying in them."*
2. The community is not educated regarding disabilities: The importance of taking action in order to change the community's attitudes towards disabilities	• The parents conduct informative meetings to educate the community regarding disabilities: *"I believe there is kindness in the world and if we could inform people about the problems we face and about how we think, I am sure we will get positive feedback."* • No respect on the disabled people: *"The people in Chios need to learn about disabilities, they must learn to respect those people. But there is still a long way to go."*
3. Fear for the future: The parents agony regarding their children's future and their proposal for a change	• *"Quality of life isn't about today but it is about creating a descent future for my child."* • Parents' proposal for an establishment of an institution for the disabled: *"I would suggest that in every part of Greece they establish an institution for the disabled, and when we are old and*

	cannot take care of our children, the community can provide them a good life"
Meta-theme II: The need for a relaxed everyday life with no stress	
Themes	**Sub-themes**
4. The importance of free time and socialization: Finding free time is difficult when living with a child with disabilities	• The parents everyday life depends on the child's needs: *"I think that based on our family's needs, there is always some free time"* • *"Limited to almost no free time"* • *"The system forces you to quit your hobbies"* • The importance of social activities for the disabled child: *"We decided to take the child in social activities instead of him going only to school and back at home"*
5. Financial well-being: Being positive and re-considering the family's priorities is fundamental for a good quality of life	• The parents income ranges between average to zero income: "*Let's say that as a family we have a medium income, we are not considered as high class but neither as a low class family"* • Good quality of life despite the

	problems: *"I think that our quality of life is good, in general we can have what we want, even though we are facing difficulties because of our child's disability"*
6. The family relationships: Task scheduling and support from the extended family are significant when living with a child with disabilities	• Support from other family members: *"From the first moment, we felt that our extended family members were supporting us"* • *"The child creates a strong bound between the couple"* • Tense at home due to the child's problems: *"We have been through a lot. Due to lack of sleep, stress and no free time we have reached a point of considering breaking up"* • Sharing every day's responsibilities: *"We share responsibilities with my husband. We have different tasks to go through everyday"*
7. The relationship with friends: Living on the island creates a more friendly environment of understanding for families with children with disabilities	• People feel connected in the island: *"Everyone knows each other. People know your problems and they show understanding, and this is positive. For example, you are*

	in the office but tired because you could not get enough sleep and they suggest that you can go home earlier" • Satisfied with the support from friends: *"After the child was born everyone has been giving support in their own way. Nobody excluded us because of our child. We are fine with that"*

Table 2. Organizing system of analysis, own-created

4.2 The need for a disability oriented welfare system for all

This meta-theme involves three main themes that emerged from the interpretation of the text and represents the parents' voices. Theme 1: The support from the state where the parents discuss about the existing infrastructures and policies and the need to reform them. The theme 2: The community isn't educated regarding disabilities, refers to the parents' initiatives on informing the community due to lack of attention given by the state. And theme 3: Fear for the future, is about the parents worries regarding their children's future at the end-of-life stage.

4.2.1 Theme 1: Support from the state

Lack of organization and infrastructure

The state provides for the education of the people with disabilities. There is the special school (from 7-15 years old) and the workshop for vocational education and training (from 15-23 years old).

The special school is characterized as one of the best special schools in the Aegean region. Inclusion was mentioned as a better educational environment for children with disabilities. Nevertheless, the parents showed very satisfied with the staff of the special school: *"The teachers love the students and they have a personal connection."*

"My child is very happy when he is getting ready for school… when he arrives there he starts hugging everyone… You can see it on his smile... This is when you see the difference between the past years and the present"

There was an argument that people who get involved with special education are more sensitive and they give love as much as possible to their students. They organize theatrical plays, muppet shows etc. There was a general belief that things are better in people's attitudes regarding children with disabilities. This change occurred due to the establishment of faculties of special needs education in both bachelor and master level. This is different than in the old times when teachers were only attending seminars in order to become special educators.

On the other hand, there is the workshop for vocational education and training. Children can attend this workshop after they are finished with the special school. Nonetheless, it was characterized as having problems in human resources, structure and organization.

There is a lack of interest regarding those problems. When this school was established, therapies and activities were included. *"The building was pretty as jewelry"* said one of the interviewees. The building did not get any maintenance and as a result it was left to get damaged.

Moreover, the therapies are not included anymore in the school building. At the moment, the students are having classes in containers in the school's yard. Regarding human resources, the school in the majority consists of uneducated and unqualified staff which was characterized as *"family business."* Moreover the parents mentioned that the years of studies were decreased from 8 to 6 which is very disappointing.

Moreover, it was stated that the existing association for sports accepts only the most functioning children excluding a lot of children with severe disabilities.

The interviewees suggested that the state needs to organize the schools. Regarding human resources the schools have to be staffed with teachers before the year start in September.

Regarding the infrastructure they need to re-build the schools to support access for disabled people. A strong discussion was regarding no age limit in education with no exclusion.

No easy access on health services

"You know how difficult it is to say to the child that we have to go for a trip to Athens to see a doctor? It isn't only the financial cost but also the psychological difficulties for us and for the child"

The island where the interview took place does not have a foundation providing health services to the disabled people and therefore, the parents are forced to go to the capital to get medical support. The need for specialized doctors in the field of special needs was discussed. The staff that is responsible for providing health services to the disabled people is unqualified. There was a denouncement about the existence of a dentist responsible for the examination of a disabled child. Specifically the dentist asked a child if he thinks he has autism.

The suggestion of an online patients system was strongly recommended in order to overcome the difficulties of getting support from the health services. The process of diagnosis is also time-consuming as well as exhausting. It was mentioned by one family that with no proper support by the state's health services and with private expenses they had to send the child's case abroad.

Disappointment and anger

The interviewees expressed their anger regarding the difficulties they face in everyday life. They reported lack of support on the disabled people. *"You get a feeling of disappointment that no matter how hard you try nothing is going to change" "The government tries to make it more difficult for us. Every year it is worse."*

The desire to go to another country was argued, where the conditions are more supportive. They feel bitter and sad because they know that all families with people with disabilities are facing enormous economic problems. No ethical support by the state was mentioned.

Living in the island has the disadvantage of not having easy access on the specific support services which makes people's lives more difficult. Moreover, the feeling of disappointed regarding the lack of infrastructures was very strong. Sometimes the students have faced

incidents dangerous for their lives. E.g. *"A wall collapsed, but thank God, the students were having a break outside of the class."*

Regarding the financial welfare support, it is disappointing and inhuman to force the parents to pay only by themselves for therapies. This is sometimes not applicable for some of the families.

Anger was also mentioned regarding the support services that keep making the families lives a nightmare. In general the families express their need for more support in everyday life by the state. They need a daily care center which can provide them the opportunity to relax in everyday life. There was a strong argument about the desire of an everyday life with no stress.

No easy access on getting financial support

"There is a welfare support system but the process of applying and getting the percentage of the child's disability is exhausting"

"I was alone in Athens holding my child in my arms and running from the one service to another to get the paperwork required"

There was a discussion about the difficulties of getting the welfare support and that the disabled people are not prioritized at all. The economic crisis was mentioned as a reason for cutting down the financial support by the state. Before 2009, the therapies provided were 20 per month but at the moment they are reduced to 5. The welfare support was characterized as *"shabby"* and that *"the economic crisis emerged the end of the welfare state."*

The need for laws regarding families with children with disabilities

"Quality of life is a well-governed state with laws where both citizens and governors live their lives by obeying in them."

There was a strong argument regarding the lack of laws and legislation for the families of the disabled. Families had the feeling that the whole system isn't making it easy for them to have access in everyday life. The existence of a corrupted system makes it even more difficult while a public service would require illegal money in order to proceed with a request.

The special school used to include a sector with psychotherapy provided for free to the public. Without any information the government decided to move those therapies to the general

hospital which is very difficult for the parents to book an appointment due to long waiting lists.

4.2.2 Theme 2: The community is not educated regarding disabilities

The parents conduct informative meetings to educate the community regarding disabilities

The importance of education regarding disabilities was mentioned. Due to lack of education the parents of children with disabilities association conducted informative meetings open to the public. Conducting informative meetings regarding autism, three years ago was significant for the sensitization of people on the island. It is mentioned that people did not even know that there is a special school on the island and that the children with disabilities can have access to education.

Informative school visits regarding disabilities are conducted by personal initiatives. There was an argument that children had no idea regarding disabilities. Only children who had siblings with disabilities seemed to be informed about people with special needs.Nevertheless, the school children's feedback from this informative meeting was very moving.

"There was one specific class that we were informed that the children are not cooperative and they would not even pay attention to us. Nonetheless, this class was proven the best of all classes we've visited! The meeting was scheduled for 45 min but it took more than an hour, with no break. This day was very emotional… The children felt safe, sharing stories, discussing… Some of them cried... It was very emotional; I remember it and I get shivers…"

Regular school visits would be everyone's desire. Therefore, even though there is support by the state people should take action and conduct those meetings. The suggestion is to assemble all associations for the disabled people into one. With shared thoughts and goals.

No respect on the disabled people

One of the basic reasons for the lack of respect for the disabled people is ignorance and lack of education. It was argued that people with disabilities face bullying at school and racism in everyday life. An example of bullying was given by a parent regarding a 30 year old person

with disabilities: *"He was sitting on the balcony when a group of kids started laughing and taking pictures of him. The person felt very upset and his mother could not calm him down. It was a terrible for both of them."*

Moreover, no respect is shown regarding the parking lots for the disabled people. Non-disabled people park in those lots without any second thought.

4.2.3 Theme 3: Fear for the future

"Quality of life isn't about today but it is about creating a descent future for my child"

It was derived from the analysis that the most important thing regarding quality of life is the future of children of the interviewed families. *"One completes life in the easiest and best possible way"* was mentioned as a definition of quality of life.

Worries regarding the future, driven by the fact that the child will be having little welfare support by the state after the parents pass away. The need for sensitized educated staff that takes care of their children was mentioned. There was a strong argument regarding the lack of infrastructure for the children's future after they are finished with their education. There are no work opportunities provided for them.

Parents' proposal for an establishment of an institution for the disabled

The need for an establishment of an institution that the children can go to after the parents pass away was mentioned. There was an argument that the disabled people in Greece are "*doomed."*

It was clear that the parents worry about what is going to happen to their children when they can no longer take care of them. There was a proposal that the state could keep the money from the welfare financial support in order to make sure that they are used to provide care to the children after the parent pass away.

The feelings of insecurity would go away only by the establishment of an institution surrounded with "*qualified people and appropriate infrastructure"* in order to provide them a *"decent life."*

4.3 The need for a relaxed everyday life with no stress

The second meta-theme emerged from the following four themes and involves the parents' voices regarding their need for a relaxed everyday life. It includes the theme 4: the family relationships where there is information regarding the relationship between the family members, theme 5: the importance of free time and socialization, theme 6: financial well-being and theme 7: the relationship with friends.

4.3.1 Theme 4: The importance of free time and socialization

The parents' everyday life depends on the child's needs

The difficulties when living with a child with disabilities were mentioned by all parents. Everyday life is based on the child's needs. "*The center of attention is focused on the child's needs."* Planning the child's everyday activities is in the center of everyday life.

Nevertheless, it was mentioned that there is free time depending on the family's needs. The child's anxiety, jealousy and fears are a suppressive factor for the family's relaxation.

"Limited to almost no free time"

The child's disabilities make it difficult for the parents to have free time. There was a strong argument about the importance task scheduling.

Quitting social activities such as going to restaurants or cafes is a fact. Free time can be provided when the children are at school during the day. Facebook as a social network is a way of communicating with other people who are facing the same challenges. There was a general confession that the families need more free time.

"The system forces you to quit your hobbies"

There aren't any daily care services provided for the families with children with disabilities. As a result, the parents have to quit their hobbies and jobs in order to stay at home with their children. People who have studied many years and have dreams regarding getting a good job are disappointed.

The importance of social activities for the disabled child

The importance of sport was mentioned as a way for the children's socialization. An association for disabled children called *"Iones"* provides a variety of sports for the children.

Nevertheless, this association does not provide individualized programs for all children. As a consequence people in their 40s and with schizophrenia or aggressive behavior, are grouped together with the small children which is very difficult to handle.

4.3.2 Theme 5: Financial well being

The parents' income ranges between average to zero income

It is significant to see the parents' financial background compared to their quality of life. After the economic crisis in 2009, the parents' income was decreased dramatically. The families include at least one employed parent in permanent or occasional jobs. Living with the disability welfare support was also a fact.

Good quality of life despite the problems

Nevertheless, most of the parents mentioned that their income is covering their expenses until now. *"I would gladly accept a higher income"* was mentioned as well as *"that in a scale from 1 to 10, I would rate my quality of life as a 3-4."* The importance of *"living an alternative life style by prioritizing our needs in order to have a good quality of life"* was given much attention.

4.3.3 Theme 6: The family relationships

Support from other family members

There was a discussion that the support provided by the family members is satisfying and not very satisfying.

The feeling of disappointment from the support from family members was mentioned as well as that raising up the child is completely dependent on the parents. There aren't any grandparents to support them, only the other siblings. Getting support only in emergencies or

holidays by the grandparents is a fact. There was an argument about creating positive feelings between the disabled child and the siblings.

It was shown that every support provided by the extended family members is welcomed: *"Getting support from the family members is significant for us to manage everyday life."*

"The child creates a strong bound between the couple"

This citation summarizes the parents feeling about the importance of family relationships. The difficulties during the diagnosis were mentioned but the support between the couple was significant throughout the process.

"I am very happy I have found a partner in life who understands", "I think it is very difficult to go through those kinds of problems without having someone by your side.

The importance of having a positive attitude is very significant for the child and for the family as a whole.

Tense at home due to the child's problems

There was an argument that without support, the family members are not relaxed and so there can be difficulties between the couple. Reasons for being tense at home are mentioned such as: *"lack of sleep", "stress", and "no free time."* These are responsible for arguments and difficulties at home.

The parents' quality of life is based on the children's problems. The importance of the way the couple handles situations like these are mentioned.

Sharing everyday responsibilities

It was argued that the couple shares everyday responsibilities. There was a discussion regarding teaching the child with disabilities how to be useful in everyday small practical tasks.

Nevertheless, if the responsibilities aren't shared, the entire work load is on one of the parents.

4.3.4 Theme 7: The relationship with friends

People feel connected in the island

The benefits of living on an island instead of a big city were mentioned. The people know each other and try to support the families any way they can. The *"respect"* the community shows to the children was argued.

Because of the challenges in everyday life there is a possibility that the parents are *"exploding on the wrong people"* but there is understanding in the relationship between the family's friends. The connection between employer and employee is strong and everyone in the workplace has understanding and provides support.

Satisfied with the support from friends

In general the parents reported satisfied with the support they get from their friends. Sometimes people have difficulties in understanding what it means to have a child with disabilities, but their friends accepted their situation nonetheless. The support they receive is mostly ethical rather than in practical things.

5 Discussion of the research findings

The interpretation of data revealed that the parents are feeling insecure regarding their children's long-term quality of life due to lack of a formal supporting system. The existence of a child with disabilities affects their everyday life, but families tend to plan and organize daily tasks in order to enjoy life. In general, the family members as well as the extended family and friends tend to give informal support to the parents emotionally and in practical things. The families discussed the need for a more relaxed everyday life as well as the guarantee that the state will provide for their children after they are not able to support them.

In the following chapters I intend to discuss the findings in the context of the literature and previous research findings. The chapter is structured based on the three main research questions:

- What do parents think about their quality of life?
- How do they perceive that a child with disabilities affects their quality of life?
- What are the parents' suggestions about improvement of their quality of life?

Moreover, the research methods used for the present study are going to be discussed.

5.1 The parents' opinions regarding their quality of life in the family

"It is not just who we are that matters to happiness, but how we think about our lives" (Diener, Lucas, & Oishi, 2002, p. 67)

The results showed that the parents perceive the notion of quality of life as a peaceful everyday life with no stress in a state governed by laws who respect the individual people's needs. Even though the state does not provide sufficient formal support for their children with disabilities, they reported somehow satisfied with their quality of life but they seemed worried about their children's future.

Diener et al. (2002) discussed three types of theories regarding subjective well-being: The need and goal theories, the process or activity theories and the genetic and personality predisposition. The need and activity theorists tend to understand subjective well-being in

correlation to the overall conditions that people live in (Diener, Lucas, & Oishi, 2002). The personality predisposition theorists argue that the people's subjective well-being is affected by the stable genetic characteristics and therefore peoples preferences.

The parents stated that a good life can be achieved through reduction of stress and by increasing positive feelings on their everyday life. This agrees with the need and goal theorists regarding reduction of negative feelings. Moreover, they added the importance of social activities and free time to meet their friends which is very important to their happiness. Indeed, Diener et al. (2002) mentioned that active participation in life tasks is very important for the people's quality of life. Previous research showed that people tend to be happier when they are involved in social activities (Diener, Lucas, & Oishi, 2002). Therefore, the parent's opinions regarding their quality of life are compatible with the two previous theories regarding subjective well-being.

Since 2009, the economic crisis affected all Greek families and more significantly the vulnerable ones who involve children with disabilities. The interviewees mentioned that their income has decreased dramatically. Nevertheless, the parents seemed to have adapted to the new circumstances in order to keep their quality of life stable. Rethinking their priorities and changing life styles is the way they tried to deal with changes. Those findings agree with Diener's (2002) discussion regarding the genetic predisposition theorists. Based on that theory, people have the tendency to be happy or unhappy. Therefore, regardless the changes in the environment, each person adapts to them and based on their personal genetic characteristics return to their biologically *"set points"* (2002, p. 67) . Those set points determine the person's perception of subjective well-being.

The parents showed fear and insecurity due to lack of support from the state. All parents feel that in order to have a good life they want to make sure that their children will be taken good care of, after the parents cannot take care of them. Based on Bronfenbrenner's ecological systems theory, the support services can be placed in the mesosystem. Therefore, the lack of support of an institution provided for the disabled affects the parents' perceptions regarding their quality of life. The interaction between the family (microsystem) and the lack of support services (mesosystem) affects the quality of life of the family.

The parents mentioned the lack of free time in order to be involved in social activities which is confirmed by previous studies as well (Ajuwon & Brown, 2012; Dardas & Ahmad, 2014). Therefore, they wish to have more time to spend with their friends as well.

Regarding the family relationships, they showed satisfied with the support they get from their partners as well as their extended families.

It was surprising that even the families with zero income agree that they have a somehow good quality of life. This fact can be explained by Diener et al. (2002) who argue that subjective well-being can be evaluated by the individuals' momentary feelings as well as their lives as a whole. Therefore, the people showed that even though they might experience difficult moments in their lives, they are staying positive and through their "*active participation in life"* (2002, p. 66) they hope for a better world for their children.

5.2 How parents perceive that a child with disabilities affects their quality of life

The results showed that the children with disabilities are in the center of attention of the families and that their quality of life depends on them. Hill (1971) argued that family is a social system and that each member has a different role in order to function and fulfil its needs. The parents mentioned the importance of sharing every day responsibilities which agrees with Hill's (1971) family systems theory.

Indeed the parents mentioned that their everyday life is affected by the disability of the child which agrees with several previous studies regarding quality of life of caregivers (Brown et al., 2006; Sulch & Kalra, 2003). Sulch & Kalra (2003) argued that one of the most significant factors who affect the caregivers' quality of life is that children with disabilities spend a lot of time at home and the parents have to provide for their basic needs.

Even though there is lack of sufficient support services, the families are flexible and ask for informal support from the extended families. This fact expands Hill's (1971) family systems theory regarding the equilibrium seeking and adaptation to changes by the families. In order to maintain a good quality of life or even to keep the balance between the members, the parents ask for informal support from the grandparents.

Previous studies on quality of life of families with children with disabilities in Greece have revealed that parents mention the lack of sufficient support by the social services which results feelings of anger and disappointment (Tsibidaki & Tsamparli, 2007). Moreover, they agreed that the extended families play a significant role on giving informal support to those families (Tsibidaki & Tsamparli, 2007; 2009).

The lack of formal support results frustration and anxiety to the families of children with disabilities. The parents have to travel to the capital twice a year in order to get medical support for their disabled children. This finding is consistent with a study held in another Greek island of Rhodes (Tsibidaki & Tsamparli, 2007).

There was also positive impact mentioned by the parents. The special school was mentioned as one of the best in the Aegean region and the parents reported satisfied with the special needs educators. The impact of having good relationship with the child's school is significant for the child and for the family. Hill (1971, p. 14) argued that the family is a *"semi-closed system"* which interacts with the environment. In this case the interaction with school can be seen as an expression of the mesosystem.

From the ecological perspective (Bronfenbrenner, 1979) the interaction between the parents and the child's school occurs in the mesosystem. If the parents create a positive atmosphere with the teachers, then it will affect the relationship between the child and the teachers (microsystem), in a positive way. Therefore, the child will feel happy at school and the quality of life in the family will be positively affected.

On the contrary as emerged from the results, the parents who did not have good relationships with the children's teachers, seemed to have difficulties in taking children at school because of anxiety issues. The children's anxiety is not a result of this relationship, but negative atmosphere can affect the relationship between the teacher and the child. From the ecological systems theory perspective there is "*reciprocity"* (Bronfenbrenner, 1979, p. 22) between people and the interaction with the environment.

The parents showed that the lack of education regarding disabilities can also affect their lives, therefore, they take private initiatives to inform the society. Hill (1971) argued the creation of new roles between the family members and society. The parents adapt to a new role, which is the informative one and take the responsibility of an attitude change regarding disabilities. Of

course this process is a long-term one, but it shows the significance of task performing (Hill, 1971).

The parents believe that the most important thing about their quality of life is their children's future. The lack of support services creates stress and anger in the family and affects their well-being. From the ecological systems theory (Bronfenbrenner, 1979), every system that interacts with another gets affected but also reforms it. Therefore, if we place the family in the microsystem and the laws regarding disabilities in the macrosystem we can see that indeed the families are getting affected by the situation.

Everyday life tasks are based on the children's needs and all families showed to have reduced their social activities due to lack of free time. This result agrees with previous studies regarding quality of life of families having children with disabilities. It was shown that parents tend to withdraw from activities that include social contact as well as quit their jobs (Dardas & Ahmad, 2014).

The family systems theory argues that the family members have different roles and are interdependent. The interviewed parents discussed that they organize their everyday tasks and they share the responsibilities. That can be linked to the task performing (Hill, 1971) characteristic of the family as a system in order to serve the needs of its members.

Having a child with disabilities can influence the relationship between the couple negatively and positively. Lacks of sleep, stress and no free time have been mentioned in previous studies as well (Dardas & Ahmad, 2014). The positive aspect mentioned was the bound that is created between the couple.

In previous studies, positive outcomes such as maturity, patience and appreciation of one's life were mentioned (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008). This can be also linked to the feelings of togetherness that the parents reported. Hill (1971) mentioned that the parents perform tasks to keep confidence and motivation high between the family members. The couples bound to each other can be explained as a mechanism that aims at creating positive feelings of confidence and strength to deal with the problems of the outside world.

Regarding the relationship with their friends, the parents argued satisfied with the support they receive due to feelings of connection between the community members. Based on my

personal experience, people create more personal relationships on the island rather than on the capital.

Surprisingly there wasn't any argument regarding religious beliefs that have been mentioned in previous studies in Greece (Tzoufi, 2005; Tsibidaki& Tsamparli, 2007).

5.3 The parents' suggestions about improvement of their quality of life.

Brown (2006) argues that in order to have a stable society the role of the family is significant. With the aim of having stable and functioning societies the state should make sure to keep high levels of quality of life.

The final objective of the study is to explore parents' suggestion about improvement of their quality of life. It is interesting to discuss the results in relation the ecological systems theory (Bronfenbrenner, 1979) as well as from the Graham's (2011) perspective on eudaimonic and hedonic policy making.

The data analysis revealed that the parents of children with disabilities suggestions for improvement of their quality of life are the following:

- Reforming existing laws and policies regarding disabilities.
- Educating the community regarding disabilities.
- Education for all people with no age limits.
- Establishment of institution for people with disabilities in every region of Greece.
- Creating centers for evening activities for all children with disabilities.
- Assemble all associations for the disabled people into one.

In the following section I intend to explore the parents' suggestions from the ecological systems theory perspective.

5.3.1 Parents' suggestions in relation to the ecological systems theory

In the ecological systems theory the world is organized in *"concentric structures"* (Bronfenbrenner, 1979, p. 22) the one contained within the other. Those structures are the four ecological systems: the microsystem, the mesosystem, the exosystem and the macrosystem (see Figure 1).

The individual is placed in the center attention. The relationships between the four systems and the individual are characterized by *"reciprocity"* (Bronfenbrenner, 1979, p. 22) which means that all systems interact with each other and also reform one another.

It emerged from the analysis that parents are satisfied with the family relationships regarding their quality of life and the support they get from the extended family as well as from friends.

Figure 3 illustrates the parents' suggestions as created from the ecological systems theory perspective.

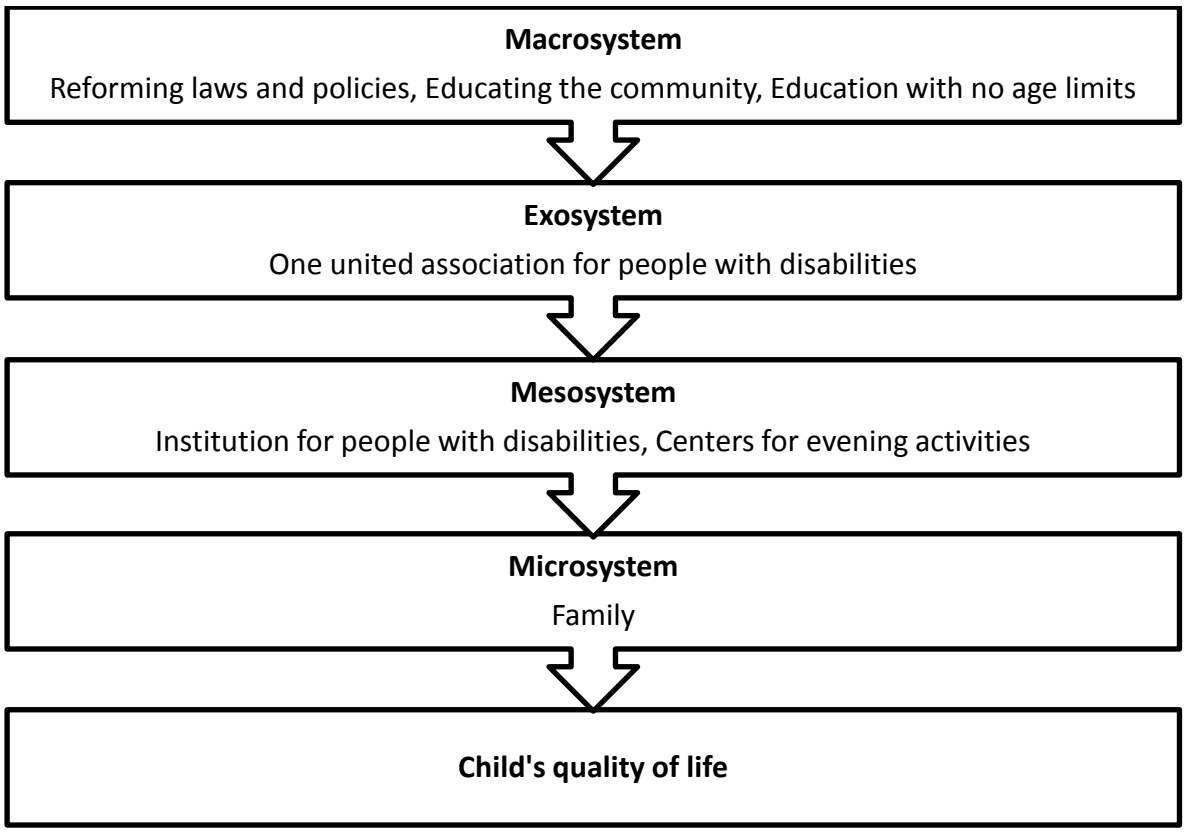

Figure 3. The parents' suggestions from the ecological systems theory perspective, own-created

Macrosystem:

1. **Reforming existing laws and policies regarding disabilities**

The macrosystem is about ideologies, attitudes and sub-cultures that exist in every context. As explained in previous chapters, all the systems are interconnected with each other and affect the development of every individual and therefore their quality of life.

The first suggestion mentioned by the parents is to reform the existing laws and policies by having the vulnerable families in the center of attention. The bureaucracy of the social services makes the processes of getting welfare support difficult for the families.

From my personal experience in Greece, people aren't sensitized regarding disabilities. The parents who raise children with disabilities are witnesses of the lack of disability oriented laws and policies.

2. **Educating the community regarding disabilities**

Due to lack of attention given to the families, there is a general attitude that people with disabilities are hopeless and have no future. When the parents conducted informative meetings at schools they figured out that only students who had children with disabilities in their families had knowledge regarding special needs.

The emphasis of all parents was on educating the community. The overall attitudes towards those families can only change if the state provides information regarding disabilities.

The Article 8 – Awareness-raising, of the Convention on the Rights of Persons with Disabilities (United Nations, 2007, p. 8), mentions that the state is obligated to raise awareness in society, to combat negative stereotypes and to promote awareness regarding the capabilities of the disabled people.

Nevertheless, the interviewees argued the lack of education provided by the state.

3. **Education for all people with no age limits**

Another issue mentioned by the interviewees is education without boundaries for all people. The parents mentioned that when their children finish their obligatory years of education, they

will have no other option in life. Therefore, the overall quality of life of the parents will be affected because their children will have to stay home.

Not providing education with no age limits is a burden to the individual person's development. Bronfenbrenner discussed this issue on his "*Hypothesis 49"* (1979, p. 288) regarding the importance of opportunities in entering settings that enable human development such as schools and universities. Therefore, both the parents and their children's quality of life will be affected.

The parents' suggestions can be placed in the macrosystem and are responsible for the children's development and affect the quality of life of the family.

Exosystem:

4. **Assemble all associations for the disabled people into one**

The exosystem refers to a context that the individual isn't involved in but gets affected by it. The parents mentioned the existence of many associations for the disabled people. Their argument is that all associations should be assembled into one, with shared goals in order become a strong and united force.

This suggestion can be placed in the exosystem because it is a setting that the child does not have face to face interactions. Nevertheless, the existence of such association will affect the child indirectly.

We can conclude that the parents' difficulties arise mostly from realities that are out of the parents' league. The parents use the mechanisms, discussed in previous chapters, to feel satisfied with their lives. However, the existing situation is affecting their well-being. That is why they suggest one united association for the rights of disabled people, so they can fight for their rights.

Mesosystem:

5. **Establishment of institution for people with disabilities in every region of Greece**

The mesosystem refers to the interaction between settings that, at least one contains the developing person. The parents mentioned the lack of an institution for their children, where

they can go to when the parents are not able to take care of them. This institution can be placed in the mesosystem because it involves the disabled child and affects the quality of life of the child and the parents. Both settings include the disabled child.

The feeling of insecurity, which arises from the lack of sufficient support from the state, affects the quality of life of the parents.

6. **Creating centers for evening activities for all children with disabilities**

The parents mentioned that they need more free time for themselves in order to feel that their quality of life is improved. Creating centers for evening activities will ensure that both the children are having the opportunity to develop their skills, but also the parents will have time to relax and get involved in recreational activities.

Microsystem:

The family is a microsystem where the interactions between the members affect their quality of life. As mentioned before, the parents reported satisfied with the support they get from the family members as well as from their extended families. Therefore, no suggestions where included in the microsystem.

5.3.2 Parents' suggestions and policy making

The parents showed satisfied with their relationship with the family members as well as with their friends. The source of disappointment and anxiety in their everyday life comes from the lack of a disability oriented welfare system for all.

Therefore, I intend to interpret the parents' suggestions for improvement through the prism of policy making. As argued in the theoretical framework, the two philosophical perspectives, the eudaimonic and hedonic views on well-being, can be implied on the public policy perspective (Graham, 2011). The state should provide for policies who aim at improving the quality of life of the citizens.

Based on Carol Graham (2011) public policy can be distributed in the ones aiming at short-term happiness and the ones aiming at long-term happiness. I agree with him that policy

making should be focusing on the long-term happiness of people as followed by the eudaimonic view on well-being.

The parents' first suggestion is the need to reform and upgrade the existing policies regarding families with children with disabilities for an educational system with no age limits. Therefore, based on Graham's (2011) argument, we can place their suggestion in the long-term happiness. The need for more disability friendly policies would gradually change attitudes and is the most significant suggestion mentioned by the parents. Combined with educating the community regarding disabilities, the parents express the need for a change in the culture. Moreover, education with no age limits also aims at long-term happiness because through education people can be included in meaningful activities and improve their abilities.

The establishment of an institution for the disabled people as well as the need for an organization providing evening activities can be placed in the short-term happiness policies.

On the present thesis it emerged that the parents seem to find ways to adapt to the changes that occur in their environment in order to feel happy in their families. Most of the difficulties arise from the system which they interact with, but they are not able to change it in the short future.

5.4 Methodology discussion

The present study has a qualitative research design with semi-structured interviews and a hermeneutic analytical approach.

The nature of the research questions is the reason for this decision, because I intended to explore the parents' opinions about their quality of life. Therefore, I believe that by interviewing and listening to people's stories I got a better overview of their subjective well-being, instead of using quantitative measurement.

To get a better insight on the families lives, I could have also used participant observation. Participant observation would have enriched the findings with information that people involved on a specific setting aren't aware that occur. Nonetheless, the participant observation data analysis can be time-consuming. Ethnographical research would require a long stay in the context in order to get a better overview of the parents' everyday life. But it may also be perceived as an intrusion into family life.

Moreover, to get a better overview of the family quality of life I could have interviewed the siblings of children with disabilities as well. I did not choose to do so, because I believe that it would be more difficult to find families that give their permission for their children to be interviewed. Adults find it easier to filter the information they want to provide to the interviewer, when children are more spontaneous on their answers and reactions. Therefore, I believe that the information gathered would include more sensitive information about the family life.

However, I argue that interviews were the best way of data collection for the present study. Interviews can provide information about the participants that comes directly from them. The data gathered includes material that is recorded and transcribed accurately. Therefore, there aren't any misunderstandings regarding the collected data. Interviews also provide the possibilities of authentication which in this study was conducted through member checks. Therefore, I could ensure the validity of the interviewees' answers.

Finding participants was not a problem, because luckily the network of people I interacted with was very open about speaking out for their problems. Therefore, there weren't any problems in the sampling process and data collection.

Nonetheless, the sample of respondents used for this study is small and all participants live on the same island. Qualitative studies intend to draw theoretical conclusions rather that generalize. I believe that by broadening up the sample by including participants of other islands of the Aegean region, I would have been able to extract theoretical conclusions that represent family quality of life in Greece.

My intentions were to explore the participants' opinions regarding their quality of life rather than generalize the study's conclusions. Therefore, I chose the hermeneutic approach for my data analysis. Hermeneutics do not aim at generalization but human understanding. On this study the interpretation of the data lead to an understanding of the participants' experiences and opinions regarding quality of life.

Concerning the data analysis, I believe that hermeneutic approach was well suited on the research questions and revealed interesting findings.

In the present study I used Maxwell's (2005) notion of rich data which involves complete and exact transcription of the recordings. I listened to the recordings many times after the

transcription in order to check any possible mistakes. Moreover, I conducted a pilot study which ensures that the interview guide can provide fruitful answers to my research questions. This process ensures the descriptive validity of the collected data.

Member checking ensured the interpretive validity by sending back to the participants the transcriptions of the interviews and ask them to correct any possible mistakes. All participants agreed that the transcriptions were not problematic. Researchers (Brink, 1993; Gibbs, 2007) suggest that member checking can also take place after the data analysis. This process could have led to a researcher's dilemma if the participants did not agree with the results of the analysis. Due to limited time I decided not to go through this step of member checking. Nevertheless, it is agreed that this step would have confirmed a higher validity of the results of the study.

Brink (1993) suggests that one of the strategies to ensure the quality of the study, besides others, is triangulation. In this study I would like to have used triangulation of data methods by using observation while interviewing the participants. Moreover, triangulation can be applied in the data analysis process. Therefore, I would like to have used grounded theory to see if the results of the analysis would have been similar.

Regarding reliability, I ensured that I ended up with exact transcriptions by hearing over and over again to the recordings while reading the documents. Moreover, I conducted peer review that gave me a more in depth understanding of my interpretations. Lastly, the external validity of the thesis was secured by clarifying the researcher's bias and the methodology.

Because of the big amount of codes created, I would like to have used definitional drift in coding, as Gibbs (2007) suggests. By using memos, I would be able to remember why I have named a specific code in a particular way. This would be very helpful and save time in the coding process.

Even though I did not face any significant problems through the study process, I believe that it would be even more interesting if I added more participants on my sample and have used open ended-questions instead of semi-structured interviews.

6 Conclusion and implications

In this chapter I will present the most central findings in relation to the research questions of the study. Moreover, the suggestions for further research will be discussed as well as the limitations of this study.

6.1 The main findings

This study explored the parents' opinions regarding their quality of life in their families. The parents reported that their everyday lives are based on their children with disabilities needs. Therefore, their quality of life depends mostly on the support provided by the state.

They reported their disappointment regarding the state's welfare support system as well as their fear for their children's future due to lack of infrastructure. Nonetheless, due to the lack of sufficient support by the state, the families tend to create informal support services that are provided by the family members as well as by the extended families.

Despite their decreased incomes, the parents showed flexibility in re-organizing their lives in order to have a good quality of life. Nevertheless, they mentioned their desire for more free time and recreational activities.

As a positive aspect in their children's lives, which affect their family quality of life, the parents mentioned the people who are involved in the special needs education. They feel satisfied with the care and love the special needs educators show to their children which makes their everyday routines easier for the families.

Lastly, the parents reported the following suggestions for improvement of their quality of life:

- The need for reformed laws and policies regarding families of children with disabilities including education with no age limits for the disabled as well as establishment of centers providing evening activities.
- The need for educating and sensitizing the community to embrace people with disabilities, by the state and by private initiatives, through one united association for people with disabilities.

- The need for an establishment of an institution for people with disabilities in every region of the country, in order to secure a good end-life stage for all people with disabilities.

The findings of the present study are compatible with previous research as discussed in Chapter 2.7. The Figure 2 shows that the most frequent themes that seem to affect the quality of life of parents are the support from the state, the family relationships, the extended families and friends.

The importance of health and financial well-being as well as insecurity feelings and anger were mentioned in previous studies as well (Rillotta et al., 2012; Steel et al., 2011)

It is interesting to mention the absence of discussions regarding influence of values as well as religious beliefs from the interviewed parents of the study. Previous research showed that religion and values have a strong impact on the Greek people's lives (Tzoufi, 2005; Tsibidaki & Tsamparli, 2007).

6.2 Suggestions for further research

One limitation of the study is its small sample of participants. This limitation arises from the nature of the qualitative research that cannot provide generalization in the entire population of families of children with disabilities. However, hermeneutics do not aim at generalizing but in understanding the participants' experiences. If the sample size is viewed as a limitation, I would suggest the use of a quantitative research design in future research, in order to get a wider understanding of the parents' opinions regarding their quality of life.

The intention of the study was to explore the parents' opinions regarding their family quality of life. Therefore, only their subjective well-being was taken into consideration. A suggestion for further research would be to measure the parents quality of life based on objective indicators.

Consequently, I would suggest further research using mixed methods approach: Qualitative open-ended interviews of parents of children with disabilities combined with quantitative questionnaires used on a bigger sample of participants.

Moreover, I would suggest a comparative study between the islands in the North - East Aegean region. The information that would arise from the data could provide important insight about the situation on a bigger region of Greece.

Another weakness of the study is the lack of direct information by the siblings of children with disabilities. As explained in the methodology discussion, I did not choose to do so due to possible difficulties that would arise from not getting the parents' consent. Nevertheless, I strongly believe that by interviewing siblings I could have gotten a more in depth understanding of the quality of life of the families. Therefore, a suggestion for further research would be a qualitative interview research including parents and siblings of children with disabilities.

The conclusion of the study implies that there is a need for awareness-raising regarding the quality of life of families having children with disabilities. The state should provide laws and policies that are disability oriented as well as educate the community regarding the types of disabilities in order to make changes in the attitudes.

Through the ecological systems theory perspective, the context in which the families live in can affect their quality of life. The parents, even though they feel disappointed regarding the formal support they receive from the state, they manage to re-organize their lives by getting support from their extended families and their friends. These interactions that occur in the families' immediate environment are supportive. Therefore, they aim at changing negative interactions in their everyday lives.

Creating a strong bound between the family members, they ensure that inside their microsystem their quality of life is secured. Despite the difficulties, they seem to hope that things will change for the better. Moreover, they showed actively involved in private initiatives that support the rights of people with disabilities.

As mentioned by the parents, quality of life isn't about today, but about creating a descent future for their children. In Greece, unfortunately, many decades of political and economic disruptions have created an unfriendly and complicated system for people with disabilities. Therefore, if the state itself does not provide support for those families, their quality of life gets dramatically affected. Creating an institution for the disabled people would create feelings of security regarding their children's future.

The parents mentioned the lack of education of the community regarding disabilities. I agree with them, that education is the most important thing that should be provided by the state. Educating people to have a critical way of thinking, to be open to new ideas, sensitive and responsible is significant, especially at times of crisis where people's ideals and values are challenged.

Education is the key that can unchain people and create healthy societies that respect individuals' needs and differences. It can, therefore, lead to a gradual change in people's attitudes regarding disabilities.

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Appendix 1: Consent to Participate in a Research Study

Title of the Project: Quality of life in families having children with disabilities: The parents' perspectives.

Researcher: Kotzampopoulou Ilektra, Mr. Phil Special Needs Education, University of Oslo.

You are invited to be a part of a research study that looks at the "Quality of life in families having children with disabilities: The parents' perspective." The purpose of the study is to find out what do the parents of children with disabilities think about their life quality and what should be done to improve it.

If you agree to be part of the research study, you will be asked to participate in one face-to-face interview at the location of your choice. The interview will be recorded. The discussion topics include specific areas of your family life: health, financial well-being, family relationships, support from others, support from services, careers, leisure and recreation, and community integration.

To ensure the validity of your answers I will provide you a written form of your answers, so that you have the opportunity to check them and correct possible errors.

To show appreciation for your collaboration I will provide the results of the research in a written form that will be send via e-mail, after the delivery of the master thesis. I hope that this study will contribute to the improvement of social support systems for you and your family members.

You may choose not to answer any interview question and you can stop your participation in the interview at any time.

We will not include any information that would identify you or your family member. To keep your information safe, the records of your interview will stay for a few hours on the audio recorder until a written word-for-word copy of the discussion has been created. As soon as this process is complete, the records will be destroyed. I will enter study data on a computer that is password-protected and uses special coding of the data to protect the information. To

protect confidentiality, your real name and your family member's name will not be used in the written copy of the discussion.

By signing this document, you are agreeing to be part of the study. Participating in this research is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. You will be given a copy of this document for your records and one copy will be kept with the study records. Be sure that questions you have about the study have been answered and that you understand what you are being asked to do. You may contact the researcher if you think of a question later.

I agree to participate in the study.

_____ _____

Signature Date

I agree to be audiotaped as part of the study.

_____ _____

Signature Date

Appendix 2: Interview Guide

"Quality of life"

1. In your own words how do you define quality of life?
2. Could you please tell me about the quality of life for your family?
    a. Do all family members work?
    b. How do you feel about the total income of the family? What do you think should be done to improve it?
    c. Does the child go to school or (if adult) have a job?
    d. Do you have free time for leisure and recreation activities?
    e. What can be done to improve home and family life
3. People arrange their family life differently, tell me: what is life quality in how you arrange home and family life?
    a. At home, how is the relationship between the family members?
    b. Do you share every day's responsibilities?
    c. How is your relationship with your relatives?
4. To live a good life you need support from others, tell me: What is life quality of support from others in your life?
    a. Do they help with everyday practical things?
    b. Do they support you emotional?
    c. What can be done to improve emotional support
5. To live a good life support from societal services are needed, tell me: What do life quality in services mean in your life?

a. Would you like to tell me if there are any health concerns in the family? (Are there any physical or mental health concerns?)

b. Are there any barriers on accessing health care and the disability related services?

c. What should be done to improve the services?

6. What can be done to improve your life quality?

Appendix 3: Permition Letter

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr: 985 321 884

Mats Granlund
Jönköping University
BOX 1026 Jönköping University
5511 HAUGESUND

Vår dato: 26.08.2014 Vår ref: 39516 / 3 / SSA Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 20.08.2014. Meldingen gjelder prosjektet:

39516	*The parents' of children with disabilities opinions about life quality in the family*
Behandlingsansvarlig	*Universitetet i Oslo, ved institusjonens øverste leder*
Daglig ansvarlig	*Mats Granlund*
Student	*Ilektra Kotzampopoulou*

Etter gjennomgang av opplysninger gitt i meldeskjemaet og øvrig dokumentasjon, finner vi at prosjektet ikke medfører meldeplikt eller konsesjonsplikt etter personopplysningslovens §§ 31 og 33.

Dersom prosjektopplegget endres i forhold til de opplysninger som ligger til grunn for vår vurdering, skal prosjektet meldes på nytt. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html.

Vedlagt følger vår begrunnelse for hvorfor prosjektet ikke er meldepliktig.

Vennlig hilsen

Katrine Utaaker Segadal

Sondre S. Arnesen

Kontaktperson: Sondre S. Arnesen tlf: 55 58 33 48
Vedlegg: Prosjektvurdering
Kopi: Ilektra Kotzampopoulou electrakotz@hotmail.com

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 39516

Based on the information we have received about the project, the Data Protection Official cannot see that the project will entail a processing of personal data by electronic means, or an establishment of a manual personal data filing system containing sensitive data. The project will therefore not be subject to notification according to the Personal Data Act.

The Data Protection Official presupposes that all information processed using electronic equipment in the project is anonymous.

Anonymous information is defined as information that cannot identify individuals in the data set in any of the following ways:
- directly, through uniquely identifiable characteristic (such as name, social security number, email address, etc.)

- indirectly, through a combination of background variables (such as residence/institution, gender, age, etc.)
- through a list of names referring to an encryption formula or code, or
- through recognizable faces on photographs or video recordings.

Furthermore, the Data Protection Official presupposes that names/consent forms are not linked to sensitive personal data.